Beliefs on Heredity in Welkom, Free State

BY

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Abstract

Introduction and Background

South Africa is a diverse country in language, culture, and beliefs. The beliefs on heredity vary widely and may in part relate to an incomplete understanding of the concept of heredity. Congenital disorders, many of which are genetic in origin, are one of the major contributors to neonatal deaths in South Africa. Which is one of the reasons why it is important to document what the beliefs of heredity are in different environments. Being sensitive towards beliefs can improve communication in healthcare service delivery. An understanding of what genetics means to members of the public should also be documented.

Objectives

1. To explore the understanding of genetics in the study community.
2. To investigate the beliefs about heredity.
3. To explore the role culture plays in the understanding of heredity.

Methodology

The study took place in Welkom, in the Matjhabeng municipality area in the Free State, where genetic counselling services are not available and currently no educational intervention on heredity has been done. The study population was foster parents from two of the prominent geographical areas in the area, namely Thabong and Welkom central. Foster parents were sampled as a convenient sample within the study communities and they are already in established groups and were therefore expected to be more open to discussion in a focus group than a group that had been randomly selected.

The study is an exploratory cohort study. The main instrument of data collection was focus group discussions (FGD). Between four and eight people made up each focus group and there was a total of five FGDs with 28 participants. The participants were grouped according to to their preferred language. The FGDs were audio recorded, the audio files were then translated and transcribed to allow

for thematic analysis. The transcripts were analysed using a coding system and themes were established.

Results

The beliefs surrounding heredity were categorized into five main themes; namely lifestyle, behaviour, familial, curses and prevention and management. Heredity is believed to be influenced by choice of lifestyle which can be passed on to a future generation. Behaviour is believed to be a heritable trait that can be traced back through many generations. Heredity is thus used as a tool to try to explain or understand a person's behaviour. Behavioural traits are also believed by some participants to represent "clan inheritance". Heredity is also seen by participants within families through familial resemblance. Genetic disorders are believed by some to be caused by curses based on cultural beliefs, however, participants also believed that these curses can be broken using prayer and rituals and thus prevented from being transferred to the next generation. Antenatal care was also considered being important in preventing genetic disorders.

Conclusion

In conclusion, cultural influences and beliefs play a role in how people understand genetics and heredity. Understanding these influences and beliefs will not only provide insight into the public's views on genetics but can also be used in implementing educational programs that can educate and inform the public about genetics.

Table of Contents

List of Tables

List of Abbreviations

CD	Congenital Disorder
ACOG	American College of Obstetricians and Gynecologists
WHO	World Health Organisation
FGD	Focus Group Discussion
AIDS	Acquired Immune Deficiency Syndrome
BDNT	Birth Defect Notification Tool
VR	Vital Registration System
HPCSA	Health Professions Council of South Africa
NGO	Non-governmental Organisation
HREC	Human Research Ethics Committee

Chapter 1: Background and Introduction

1.1 Congenital Disorders in South Africa

Statistics confirm that congenital disorders (CDs) are one of the leading causes of neonatal mortality in South Africa. An estimated 11.24% of neonatal deaths in infants weighing more than 1 kg occur because of a congenital disorder. Despite this incidence and the fact that an estimated 70% of CDs can be treated if screening and proper early detection are done, CDs still do not receive the attention required from health authorities. (Malherbe, Christianson, Aldous, & Christianson, 2016).

1.2 Genetic Services in South Africa

Although there is a need for medical genetic services, these services are only available at tertiary hospitals. These services should be implemented in at least at secondary health care facilities, if not at a primary healthcare level, as many children are being left undiagnosed when they reside far from a tertiary facility (Malherbe, Christianson, Aldous, & Christianson, 2016). According to the National Policy Guidelines for the management and prevention of Genetic Disorders, Birth Defects and Disabilities 2001, genetic services should be made available particularly before conception, during pregnancy, at the time of birth and during childhood and adolescence. Lack of funding and other medical priorities such as HIV/AIDS have limited genetic services (Kromberg, Sizer, & Christianson, 2013). Not only does the lack of funding affect patients' utilisation of medical genetic services but engaging with services can also be influenced by cultural background, education level, and language(Morris, Glass, Wessels, & Kromberg, 2015).

As previously stated CDs are one of the leading causes of mortality of neonates in South Africa. This is one of the reasons why it is important to start implementing better genetic service facilities across the country in South Africa. A challenge for South African genetic counsellors the need to try to make the concept of heredity more understandable and applicable to a population that is not only diverse in culture, but diverse in language too (Greenberg, Kromberg, Loggenberg, & Wessels, 2012). Another

difficulty is the lack of documentation and awareness of different beliefs related to heredity; for example, that a genetic disorder may be the result of punishment by the family's ancestors (Morris, Glass, Wessels, & Kromberg, 2015).

The common sense model of self-regulation shows that a person's beliefs and perceptions will influence their healthcare choices (Ayode, et al., 2012). This is why it is important to document people's beliefs as it will affect their health care uptake. Genetic services in South Africa should incorporate a social model of health, which acknowledges social and cultural factors and the influence it has on a person's healthcare decision (Wade & Halligan, 2004).

1.3 Heredity and beliefs

There are many definitions of what a belief is; according to the Oxford dictionary a belief is "something one accepts as true or real, a firm opinion". One's beliefs should be handled with sensitivity in all healthcare settings and never be disregarded. Being sensitive towards beliefs can help prevent a communication barrier in healthcare service delivery (ACOG Committee Opinion: 49, 2011).

The beliefs on heredity vary widely, which may be related to an incomplete understanding of the concept of heredity. Penn et al. (2010) documented traditional beliefs on the causes of various genetic disorders. Interestingly, in this study, the participants believed that eating "incorrectly" or eating "culturally forbidden food" was the reason for genetic disorders.

Beliefs differ vastly across the African continent many of which affect how people who have a congenital disorder are treated. For example, people in some East African countries believe that people with albinism provide their countries with divine protection and were therefore sent by God or the ancestors, whereas those in more Southern African countries more often believe that albinism is a punishment(Kimbassa, 2013).

1.4 Purpose of Research

There are three schools in the Matjhabeng area that cater to children with both intellectual and physical disabilities. Upon speaking informally to parents who have a child with a disability before the study was undertaken, it was evident that these parents did not fully understand the cause of their child's disability many of which are likely genetic. This suggests that an educational intervention is needed and that documenting the beliefs and knowledge regarding heredity in this community could bring value to such a program. As discussed, congenital disorders are one of the leading causes of neonatal deaths in South Africa, many of which are genetic. Therefore, understanding what local people believe contributes to the cause of CDs and how they perceive heredity is important. Beliefs can differ between individuals and between cultural groups. The general understanding of what genetics means for members of the public should also be documented. The results from this study will contribute to this body of knowledge and could also provide information on how to make educational interventions more locally relevant and could provide a background into the role that culture, plays in the understanding and beliefs of heredity.

Chapter 2: Literature Review

The purpose of this chapter is to provide an overview of heredity and genetics with a focus on the South African health care setting, as well as beliefs regarding heredity and how they may play a role in health care.

This literature was compiled by using several sources of information. These included South African government websites, websites relating to health such as the World Health Organisation (WHO) as well as academic and peer-reviewed journals which were accessed through the following search engines: PubMed, EBSCOhost and Google Scholar. Search terms and phrases used, but not limited to, included: heredity, heredity beliefs/views/opinions/thoughts/feelings, beliefs in healthcare, effects of beliefs in healthcare, genetics, beliefs on genetics, genetic policies South Africa, beliefs on healthcare in South Africa, beliefs on heredity/genetics in South Africa.

2.1 Genetics and Heredity

Heredity is the genetic transmission of characteristics from parents to their children. Genetics is the study of how these heritable characteristics are passed on from parent to the child. Heredity helps explain why children look like their parents but more importantly it provides an explanation of how a disorder may run in the family and includes an inheritance pattern. Inheritance patterns can range from simple to complex. Some genetic disorders may be caused by a mutation in a single gene which may be passed on to the next generation (Bagley, 2013) while other disorders have a more complex inheritance pattern.

A mutation is a permanent alteration to a genetic sequence that can occur in only a single DNA base pair or may extend to a large section of a chromosome that can include numerous genes. Genetic mutations can be classified into two broad categories; namely heritable or germline mutations and acquired or somatic mutations. A germline mutation is often inherited from one's parents and will be present in all cells throughout one's life and have the potential to be passed on to the next generation.

In contrast, an acquired mutation develops during one's post conception life and may be due to environmental factors. Somatic or acquired mutations are not heritable in that they are not present in the gonadal cells that will make up the next generation. (Genetics Home Reference, 2018).

Heredity is often associated with a genetic predisposition to disease. Genetic predisposition is the probability of developing a specific disorder based on one's genetic composition. Genetic predisposition is based on specific genetic variations which were inherited from a parent. These genetic variations may contribute to the development of a disorder by increasing susceptibility but are not necessarily the direct cause of the condition. For example, a family history of breast cancer that is often associated with a mutation in the BRCA1 and BRCA2genes increases the risk of developing breast cancer considerably, but it is not inevitable that women carrying the mutation will develop cancer (Kriege, et al., 2004).

2.2 Congenital and Genetic Disorders in South Africa

A congenital disorder is an abnormality of structure or function present at birth and can be caused by genetic factors such as chromosomal abnormalities or single gene defects or teratogens such as alcohol use during pregnancy or other environmental factors that affect the development of the foetus(Malherbe, Aldous, Woods, & Christianson, 2016). Even though CDs are one of the leading causes of neonatal mortality, there is no national registry maintained for CDs in South Africa, but the estimated birth prevalence of significant CDs is 53.4 per 1 000 live births. Birth prevalence is defined as the number of infants born with a birth defect per 1 000 live births and allows for a comparison between populations(Christianson, Howson, & Modell, 2006). This estimate was calculated using hospital-based data rather than population-based studies due to the lack of birth-defect registries and/or surveillance suggesting that the estimated birth prevalence is an underestimation of the true prevalence (Kromberg, Sizer, & Christianson, 2013). Oculocutaneous albinism is the most common autosomal recessive disorder (Manga, Kerr, Ramsay, & Kromberg, 2013). This type of albinism has a prevalence rate of one in 3 900. It has also been found that the prevalence rate differs amongst

ethnicities. The prevalence is higher in Sesotho populations compared to isiXhosa populations (Hong, Zeeb, & Repacholi, 2006). Despite how common CDs are, there is still a lack of pre-conception screening, prenatal screening and early diagnosis in South Africa. (Malherbe, Christianson, Aldous, & Christianson, 2016). Based on the modeled estimate, there should be over 18 000 cases of CDs identified and reported annually in South Africa. However, in 2012, only 2 174 cases were reported confirming either the poor identification of CDs or significant under-reporting or probably both (Malherbe, Christianson, & Aldous, 2015). In 2001 the National Department of Health implemented the Birth Defect Notification Tool (BDNT) form. The BDNT was designed for medical staff to record the age of the patient and the type of CD at delivery or during neonatal follow-up. A list of CDs that can be identified or are measurable within 24 hours was compiled. Some of the CDs listed included albinism, Down syndrome and microcephaly. In 2014 only 612 CDs were reported using the BDNT while 84 461 notifications were expected based on the estimated prevalence. This suggests poor implementation and inadequate use of the BDNT (Lebese, Aldous, & Malherbe, 2016).

According to WHO, globally CDs cause the death of nearly 500 000 children under the age of five annually with more than one out of ten new-born babies dying from a CD(World Health Organisation, 2016). The United Nations estimates that 8.6% of deaths of children under the age of five worldwide is the result of congenital anomalies (World Health Organisation, Congenital Anomalies, 2015). By comparison, Acquired Immune Deficiency Syndrome (AIDS) is the cause of 8.7% of deaths under the age of five. Data from the Vital Registration system (VR) in South Africa indicates that, in 2015, of the deaths in children under the age of five, 5.9% were caused by CDs, 1.2% were caused by HIV/AIDS and 10.1% were caused by gastroenteritis (Bamford, McKerrow, Barron, & Aung, 2018). The VR is a system that provides data on mortality in South Africa. The VR not only records the number of deaths but also the cause of death of both children and adults (Joubert, et al., 2012). This data confirms that CDs are a leading cause of death in young children and require more attention. A

2.3 Genetic Services in South Africa

Although limited, genetic services available in South Africa include medical genetic clinical services, prenatal, diagnostic, predictive and carrier genetic testing and genetic counselling services. Genetic services are not only a pivotal tool in aiding a diagnosis, but it can also be used to determine a predisposition to a disorder or to determine if a person is a carrier of a disease-related mutation. Genetic testing can also be used to determine what the probabilities are of a child being born with a certain disorder based on the parents' genotypes(Witherington, 2014).

Although there is clearly a need for medical genetic services throughout the country, these services are currently only available in a few higher income urban areas at certain tertiary hospitals but should be implemented in less resourced areas where many people are left undiagnosed and where CDs are poorly managed (Malherbe, Christianson, Aldous, & Christianson, 2016). According to the National Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects, and Disabilities (2001), genetic services should be made available throughout the life cycle but, in particular, pre-conception, during pregnancy, at birth and during childhood and adolescence. The lack of health care funding and other overwhelming medical priorities such as HIV/AIDS have contributed to reduced access to genetic services for much of the population(Kromberg, Sizer, & Christianson, 2013). The National Policy Guidelines also recommends a national, primary health care orientated medical genetic service that would aid in the diagnosis, management, and prevention of genetic disorders. The main aim of the Human Genetics Policy Guideline for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities of South Africa (2003) was to advise on integration of genetic services into a primary health care setting and defined three important goals. First is to reduce the birth incidence of genetic disorders and birth defects in South Africa; second is to ensure that individuals who are affected by a genetic disorder or birth defect are empowered and last is to create greater awareness of the psychosocial and economic impact that result from genetic disorders. The policy also defines priority conditions which include Down Syndrome, Foetal Alcohol Syndrome,

and Albinism and identifies those sectors of the population most likely to benefit the most from having comprehensive medical genetic services available.

There are only four academic genetic centres which provide training across South Africa and, although there is an ongoing training of medical geneticists and genetic counsellors, the number of registered practitioners is currently only about a fifth of what the WHO recommends. WHO recommends that there be two genetic counsellors per one million people which implies there should be at least 100genetic counsellors in South Africa whereas in 2013 there were only 22 registered with the Health Professions Council of South Africa (HPCSA) (Macleod, 2013). The Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities (2003)recognised the lack of staff available to provide a comprehensive genetic service in South Africa. These guidelines suggested that an additional 70 medical geneticists and an additional 300 nurses trained for genetic counselling as well as 300 laboratory scientists would be required just to meet WHO recommendations. Despite the fact that there are family planning clinics throughout the country, genetic pre-conception care is scarce (Kromberg, Sizer, & Christianson, 2013). In 2013, it was reported that South African genetic services were deteriorating when compared to another seven emerging economy countries while a decrease in funding had also affected the genetic laboratory services nationwide (Malherbe, Christianson, & Aldous, 2015).

Lack of funding and staff for comprehensive medical genetic services are one reason for limited access but stigmatisation of genetic screening may also prevent people from using those services that are available. According to DiMillo et al. (2013), people fear stigmatisation by anticipation, rejection, and association. People fear what outcome such stigma may have and may fear rejection from society and are as a result, not willing to be associated with the source of stigma. The way people perceive the process of genetic screening may be influenced by their cultural background, education level, and languages well as the healthcare setting (Morris, Glass, Wessels, & Kromberg, 2015). It is important to

make sure there is a good understanding of the value of genetic services and to address the potential stigma that could be associated with using these services. In a study by Gillham et. al. (2015) the authors wanted to determine factors that influence the uptake of genetic counselling and carrier testingHaemophilia Comprehensive Care Centre at Charlotte Maxeke Johannesburg Academic Hospital. The study population was female relatives of people who have hemophilia. Of the participants who had never been for genetic counselling, some of the reasons amongst were they were not aware of the services, or they were afraid of the outcome (Gillham, et al., 2015).

As described by Penn and Watermeyer (2012) what happens within each genetic counselling session is affected by broader factors such as socio-political, family and culture, language and institutional. All these factors may be potential barriers and may affect how a patient perceives the process. The authors also suggest that South Africa makes use of a local model rather than a universal model for genetic counselling(Penn & Watermeyer, 2012).

A genetic counsellor should present genetic information in an easily understandable manner and can often be seen as a "translator" as the concept of genetic concepts may frequently be viewed as complex (Rantanen, Pontinen, Nippert, Sequerios, & Kaarianien, 2009). South African genetic counsellors have the task of trying to make the concept of heredity more understandable and applicable to a population that is diverse in culture and language which can be challenging (Greenberg, Kromberg, Loggenberg, & Wessels, 2012). Other factors that genetic counsellors need to consider are; patients' beliefs around reproduction and on disease causation, as well as the use of traditional healers and medicine (Kromberg & Wessels, 2013). The beliefs around heredity are important to consider in genetic counselling(Morris, Glass, Wessels, & Kromberg, 2015). Genetic services in South Africa often include cross-culture counselling, therefore it is important that the genetic counsellor has knowledge into cultural practices and beliefs (Kromberg & Jenkins, 2012).

2.4 Beliefs on Heredity

Every culture has phrases that describe the power of heredity; for example, "the apple doesn't fall far from the tree". Such phrases come from many years of observing human behaviour and noting that

genes influence behaviour as they are passed on from generation to generation (Mitchell, 2018). In South Africa, there is diversity in culture, language, and beliefs. The beliefs on heredity vary widely. Apart from the widespread belief in the biomedical model, religious and cultural beliefs play a pivotal role in how a family perceives a congenital disorder and the cause thereof (Bhat, 2015). Penn et al. (2010) documented traditional beliefs on the causes of various genetic disorders in South Africa. This study was qualitative and made use of focus group discussions to obtain the data. Three focus groups of 15 grandmothers participated in the discussions. The grandmothers were from different linguistic and cultural backgrounds but are considered a representative sample of the study community. Some participants in this study believed that eating "incorrectly" or eating "culturally forbidden food" was one of the causes of albinism, cleft lip and palate and cerebral palsy. Many of the beliefs about possible causes of a genetic disorder related to the mother, for example, that the mother had misbehaved during the pregnancy. Other common beliefs identified in this study are related to ancestors or to God. For example, albinism was seen either as a punishment or as a gift from God or the ancestors, while club foot and cleft palate were usually seen as a gift from God. Down syndrome was believed to be caused by "combining different blood", either because the parents are from different cultures or as a result of incest (Penn, Watermeyer, MacDonald, & Moabelo, 2010). In his review paper on albinism in African countries with the main focus on South Africa, Kimbassa (2013) concluded that the most commonly believed causes of albinism were that the mother had done something "incorrect" during pregnancy or that the condition was the result of an action by the ancestors or by God. There are many superstitions regarding albinism and people who are born with the condition often face prejudice (Kimbassa, 2013). In a South African study that aimed to document the beliefs and stereotypes surrounding albinism, participants included were university students from Johannesburg; some with albinism and others without albinism. The participants who have albinism understood their condition yet still described themselves as "cursed" or "outcasts". Some of the participants who do not have albinism admitted that, despite not knowing much about the condition, they believed that it

is caused by either looking at a person with albinism while pregnant or by a curse (Phatoli, Bila, & Ross, 2015; Fottrell, Tollman, Byass, Golooba-Mute, & Kahn, 2012).

In a study conducted by Fottrell, Tollman, Byass, Golooba-Mute, and Kahn (2012) the authors conducted verbal autopsies to explore "bewitchment" as a cause of death in Mpumalanga, South Africa. This study explored the epidemiology of 6874 deaths reported to be caused by bewitchment. The authors concluded that bewitchment was attributed as the cause of death in children and women of reproductive age. The death of pregnant women was also attributed to bewitchment. In their closing comments, the authors stressed the importance of understanding people's perceived beliefs on the aetiology of illness and death in order to improve health promotion efforts (Fottrell, Tollman, Byass, Golooba-Mute, & Kahn, 2012).

A study that aimed to document the understanding of genetics and inheritance amongst Xhosa-speaking caregivers of children with haemophilia found that,although there was a lack of understanding of what genetic inheritance really is in this group, participants believed that physical characteristics and behavioural traits can be passed on from parent to child (Soloman, Greenberg, Futter, Vivian, & Penn, 2012). As documented by Kromberg and Jenkins (2012), there are sociocultural issues in South Africa that can affect the process of genetic counselling. These include a patient's system of thought such as a strong belief in destiny, fatalism and communal decision making and their belief on disease causation. The cause of a disease is often attributed to the ancestors. There are many beliefs as to why the ancestors may "cause" illness. One of the beliefs is that the ancestors are angry because there was a transgression of cultural rituals. There are many common practices and taboos that can influence a person's beliefs regarding inheritance; for example, there is a belief that eating rabbit meat during pregnancy will prevent the child from having long ears and teeth. Myths and superstitions can affect the process of genetic counselling, especially with regard to the understanding of inheritance. If a woman fully believes that her child received everything from the father and she

was just an “incubator”, she will not easily understand why her child has a certain disorder if there is no history of the condition on the father’s side of the family (Kromberg & Jenkins, 2012).

The beliefs across African countries differ vastly well; for example, in southern African countries albinism is seen as a punishment on the family, whereas in some East African countries people with albinism are believed to provide their countries with divine protection and are therefore sent by God or the ancestors(Kimbassa, 2013). Beliefs elsewhere in the world may also be very different. For example, babies born in India with additional limbs are believed to be incarnates of particular Hindu deities and recurrence of congenital abnormalities in a family is often blamed on bad “karma” (Bhat, 2015).

A person’s beliefs should not be disregarded in a healthcare setting and should be handled with sensitivity. Being sensitive towards beliefs can help to prevent a communication barrier in healthcare service delivery (ACOG Committee Opinion: 49, 2011).

2.5 Cultural Sensitivity in Healthcare

It is well known that there is a need to educate the public about the role that genes and the environment play in disease causation. In a systematic literature review published on perceived barriers in integrating genetic services, Mikat-Stevens, Larson, and Tarini (2015) found that patient knowledge was perceived as a barrier 38 of the articles that were included in their review. Other barriers that were reported included a lack of access to genetic services, patient anxiety related to genetic risk and not having enough time with a patient (Mikat-Stevens, Larson, & Tarini, 2015).

According to the Common-Sense Model of Self-Regulation (CSM), beliefs and perceptions about causation of illness will influence a person’s action to re-mediate health issues. These beliefs and perceptions are obtained socially and are maintained through interpersonal communication in a social context. It is thus important to consider beliefs and perceptions about health in any healthcare system (Ayode, et al., 2012). The CSM offers a conceptual framework for investigating an individual’s management of an ongoing or future health-related issue (Leventhal, Phillips, & Burns, 2016). An

example of using the CSM is understanding that in African cultures being in good health does not only mean physical health, it also means being in good standing with the ancestors as well as living in agreement with the standards and customs of the traditions of that society (White, 2015). It is important to be aware of a patient's beliefs to not only be respectful but also because their beliefs may dictate the treatment plan that will be used (Teferra & Shibre, 2012).

The biomedical model of health focuses on the physical and/or biological causes of disease and although this approach to healthcare has made technological advancements for the field, the perceived reasons for the disease are not always well addressed in this model. The social model of health considers the broader influences on healthcare such as social, cultural and environmental influences (Wade & Halligan, 2004). Beliefs have been found to influence how a patient understands a disease. Beliefs can influence a patient's health care decision making and can influence their coping strategies (Puchalski, 2001). Hordern (2016) stresses the importance of obtaining a patient's social, cultural and spiritual background during history-taking as a patient's beliefs may prevent them to seek medical care however their beliefs can also be used to promote adherence.

Many factors besides culture affect health-seeking behaviour and include the cost of the services, the distance to the facilities, level of education and even the adequacy of the facility, such as whether there are enough staff and medical supplies. In this cross-sectional study conducted in Uganda using structured questionnaires, the authors considered factors that affect health-seeking behaviour (Musoke, Boynton, Butler, & Musoke, 2014). These authors also suggested that many of these factors can be addressed by having more frequent mobile clinics and strengthening relationships between health care workers and community members. In a review paper published in 2012, Kumar and Preetha suggested additional ways of addressing these factors such as health promotion which should have a setting-based approach such as in schools, hospitals, workplaces and even residential areas (Kumar & Preetha, 2012). In planning and delivering genetic services in South Africa, not only should

the patient's beliefs and knowledge be taken into consideration but other factors such as distance from the facility must be considered to ensure that services are both comprehensive and well utilised.

Cultural sensitivity in healthcare also extends to people's use and beliefs in alternative medical practices such as traditional medicine. In South Africa, it is estimated that 80% of the population makes use of traditional medicine and in most cases, traditional medicine is the source of primary health care. The reason why so many people make use of traditional medicine is that it is easily available and affordable, and it provides a good alternative to Western medicine(Sobiecki, 2012). It is estimated that, in South Africa, there are over 200,000 traditional healers practicing. Traditional healers are generally well respected within their communities (Truter, 2007). Traditional healing is a holistic approach, looking at all aspects of the individual rather than just the physical presentation (Lange, 2018). Traditional medicine is widely used throughout the world with each country having their own unique remedies. The World Health Organisation (WHO) defines traditional medicine as " the sum total of the knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness"(WHO, 2014).

2.6 Summary

The following observations were made during the literature review:

1. CDs are one of the leading causes of mortality amongst children under the age of five in South Africa.
2. There is limited data about CDs available in South Africa.
3. The genetic services currently available in South Africa are inadequate.
4. There is insufficient knowledge of the beliefs and understanding of heredity amongst the different cultural groups in South Africa.
5. The data that is available can often not be generalised as it is specific to a cultural group or setting in which the study was conducted.

6. Healthcare services should be more culturally sensitive and take other beliefs of disease causation into consideration.
7. Genetic services in South Africa should incorporate a social model of health, which will acknowledge social and cultural factors that influence a person's healthcare decision.

In conclusion, this review highlighted that South Africa needs more comprehensive medical genetic services that should be implemented at a primary health care level. It highlights the importance of these services being culturally sensitive but indicates that there is limited data in this regard. Documenting what people in different settings in South Africa believe and understand about heredity/ genetics is important in developing the most appropriate services for the South African population.

Chapter 3: Methodology

In this chapter, the aim and objectives of the study are listed, and the methodology used is described.

3.1 Aim

The study aimed to determine what the beliefs about heredity are amongst selected ethnolinguistic groups in the mining city of Welkom, Free State.

3.2 Objectives

1. To explore the understanding of genetics in the study community.
2. To investigate the beliefs about heredity.
3. To explore the role culture plays in the understanding of heredity.

3.3 Study Design

The research question was explored qualitatively. Qualitative research has the characteristic of having the respondents as active participants rather than subjects (Ulin, Robison, & Tolley, 2005). This study met these characteristics as people's knowledge, as well as their understanding of the topic, was explored by active participation in a focus group.

The philosophical orientation chosen for this research question was the interpretive perspective. The world in this paradigm is constructed, interpreted and experienced by people's interactions with each other as well as with their social systems. This paradigm is therefore subjective. The way particular individual views and experiences the world, will be different from another person (Ulin, Robinson, & Tolley, 2005). People may construct different meanings for the same phenomenon and in this way, the world is dependent on our knowledge (Scotland, 2012).

The study was an an exploratory cohort study. A cohort study is a descriptive study done in the present. To ensure rigor or trustworthiness, a qualitative study should have credibility, transferability, dependability, and confirmability(Shenton, 2004). The credibility of the study was ensured with the use of open-ended questions, prevent swaying the participants in a particular direction and to ensure

that their own beliefs and views were heard. It may be hard to transfer or generalise this study as the data isn't a true representation of the South African population due to the low variation of ethnolinguistic background in the groups and because the sample groups are small. Data saturation was however achieved. Initially, three focus group discussions were conducted and then an additional two focus groups followed. No new themes came from the additional groups, so no new insight was gained. To ensure objectivity, the focus group discussions were facilitated by a third party. The facilitator did not know the participants before and therefore had no influence over them.

3.4 Setting and Study Population

The study was conducted in Welkom, in the Matjhabeng municipality area in the Free State, where genetic services are not available and currently no educational intervention on heredity has been done.

Welkom is the second largest city in the Free State. It is one of six cities/towns to fall under the Matjhabeng municipality service area (Lejweleputswa District Municipality, 2017). There are two large, well defined peri-urban areas in Welkom, namely Thabong and Welkom Central. According to the 2011 census, 75 398 people stay in Welkom, while 126 013 people stay in Thabong, making these two areas the largest populated areas of Matjhabeng (2011 Census, 2011). It is estimated that 66.5% of households are "formal" and 23.1% are "informal" (Department of Rural Development and Land Reform, 2013). The Matjhabeng municipality is more commonly known as "the Goldfields" as this area is the hub of mining for the Free State. The mining sector is the dominant economic contributor to the region. The unemployment rate was 37% in 2011 and has been said to have increased due to the foreclosure of mines in the area (Housing and Development Agency, 2014). There is a disproportion in the average household income in the area, with 21% of the population earning less than R3 799per month and 31% of the population earning more than R71 000 per month (Demographics, 2014). According to the 2011 census, Sesotho is the most common first language (58.3%) followed by Afrikaans (14.6%) and then isiXhosa (13.6%).

There is no tertiary hospital in the area and although the secondary hospital in the town offers prenatal screening such as ultrasound examination, medical genetic services are only available at the tertiary referral hospital which is approximately 200km away in Bloemfontein. In a study that was conducted in Welkom and QwaQwa, the authors wanted to determine the utilisation of health care in the area with regards to HIV treatment. 76.7% of the individuals made use of public facilities, 18.2% made use of private healthcare facilities, 0.7% made use of traditional medicines while 4.4% did not even seek healthcare (Visser & Booysen, 2004).

The study population was foster parents from Thabong and Welkom Central. Engo is a non-governmental organisation (NGO) that was approached to gain access to the foster parents. The NGO provides social services such as prevention, protection, care, development and treatment programs for individuals, families, and communities in the Welkom area. The fostering program provides a secure environment for children who have been removed from their homes until adoption has been finalised. Foster parents undergo a screening process to ensure that they are able to take care of the child and cater to their needs should they be disabled. The foster parents then have monthly support sessions and are therefore a close community. Foster parents were chosen both as a convenient sample and, because they already participate in an established group, it was thought that they would be more likely to communicate openly with each other than a group that was randomly constituted. Focus group discussions (FGD) that are conducted with participants from an established group tend to be more successful as the participants are more comfortable and therefore talk more (Stewart & Shamdasani, 2014). Another aspect of using an established group is that there is already formed a trust which also creates an openness to answer (Sinner, Prochazka, Paus-Hasebrink, Farrugia, & Farrugia, 2013).

Between four to eight foster parents made up each focus group and there were three focus groups conducted in Thabong and two focus groups were conducted in Welkom Central. The ideal size for a focus group is five to eight. Smaller focus groups are found to be more comfortable for the participants

(Kreuger & Casey, 2015). The participants were asked what their preferred language of communication was. Sesotho was the most popular choice although some participants did speak isiXhosa and English. The group facilitator was fluent in all these languages and was able to understand and engage all the participants in the discussion. Four of the FGDs were predominantly Sesotho speaking and one FGD was predominantly made up of isiXhosa speakers. A guideline which contained questions and possible probing questions for the focus group was designed (Appendix B). The aim of the guideline was to provide the facilitator with direction and also to help her if she found it difficult to talk to the participants. Each FGD was audio recorded. The focus groups took place in a predetermined venue convenient for the participants. For Thabong the local library was used and for Welkom Central, the NGO's boardroom was used.

3.5 Recruitment

Foster parents were first contacted by the social worker from the NGO for an information session on the study, which was held after one of their monthly meetings. The social worker was given all the information about the study which she then shared with the potential participants. They were then given the opportunity to decide about participating in the study. 55 foster parents were invited to participate; 28of these elected to participate. Five focus groups were conducted, with the group size ranging from four to eight participants per group. No reasons were given by the foster parents who did not wish to participate in their decision. It may have been related to the inability to attend the FGD due to work commitments, or they may just not have been interested in participating.

3.6 Consent Taking

Informed consent was taken by the group facilitator, Nelly Mahlatsi, from each participant before the focus groups commenced. Mrs. Mahlatsi is a retired nurse who now engages in community education programs and often facilitates discussions about health with various communities. Mrs. Mahlatsi is fluent in English, Afrikaans, Sesotho, and isiXhosa. The consent forms (Appendix C) were available in

the participants' first language (English, Afrikaans, Sesotho, and isiXhosa) and any questions they had were answered. Voluntary participation was emphasised.

3.7Data Collection

The instrument of data collection was focus group discussions (FGD). The FGD was semi-structured to allow for the exploration of the topic and for some uniformity between the FGD. This meant that results were then easier to compare and to identify common themes (Ulin, Robison, & Tolley, 2005). A semi-structured FGD is flexible and allows for the exploration of issues that come about spontaneously. The open nature of an FGD allows for more in-depth responses and, in return, rich data to be analysed (Doody & Noonan, 2013). Focus groups are inexpensive and it is a fast method of acquiring data. Participants may feel more comfortable in voicing their opinions in a group rather than in an individual interview. FGDs are a well-suited method for this study as the participants know each other and are familiar with group discussions. Focus groups also allow participants to reflect on each other's viewpoints. The researcher or facilitator can clarify and reflect back on topics. It allows for an in-depth look into the research topic (Mercè, 2017). One limitation of a focus group is that it relies on the assisted discussion in order to get results. In addition, outspoken individuals may dominate the discussion. Another limitation could be that focus groups cannot always be repeated to produce the same data so the validity of the research may be questioned. Variable participant selection methods may make it harder to generalize results (Leung & Savithiri, 2009).

The FGD structure was to open discussion with primary questions and then move on to secondary questions. According to Stewart and Shamdasani (2014), primary questions are used as an introduction to the topic and secondary questions are typically open-ended question which will then require greater detail in answering. Open-ended questions were used to drive the discussion and allowed participants to talk about their views without being constrained. Open-ended questions are often used in FGDs as more data is obtained using open-ended questions (Stewart & Shamdasani, 2014). The facilitator made use of locally relevant examples to keep the participants focused on the

topic. The combination of examples and open-ended questions allowed for the FGD to follow a type of conversation setting. The facilitator remained objective and respected the participant's views which created trust between the facilitator and the participants. Although the researcher was present at the FGD venue, the researcher did not partake in the FGD, but was rather there to answer any questions after the FGD and to provide clarity should there have been questions that the facilitator was unable to answer.

3.8 Thematic Analysis

Data recordings from the focus groups were transcribed and translated. The audio recordings were given to two different translators who have a degree in linguistics and experience in translating audio files. Each transcriber translated and transcribed independently. Their transcriptions were then exchanged electronically. The transcripts were then compared to ensure accuracy. The focus group facilitator, Mrs. Mahlatsi also read through the transcripts to ensure that no data was missing.

An inductive approach to thematic analysis was taken. This means that the themes were developed according to the content of the data (Maguire & Delahunt, 2017). To analyse the transcripts the following method was used: The transcripts were first read through thoroughly and repeatedly. Relevant and repeated sections were then high-lighted and grouped together and assigned a label, thus generating codes. Each code was then categorised and emerging themes were identified. Three of the transcripts were given to the co-supervisor who independently analysed them to not only provide suggestions but also to challenge the researcher’s ideas. The results are discussed in chapter five.

Chapter 4: Ethical Considerations

4.1 Ethical Review

This protocol was reviewed and approved by the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee (HREC). Reference number 802/2017 (Appendix A)

4.2 Informed Consent

Informed consent was obtained before the focus group discussions were conducted. Participation in the research study was voluntary, and the participants had the free will to leave the focus group at any time. Participants were also informed that should they no longer wish to participate, the views that they shared would not be used for the study. Participants were also informed that the session will be audio recorded and the audio files would be stored. All the information given to the participants is also in the consent forms. Once everything was explained to them, and any questions answered, the participants then signed their consent forms.

Participants were informed about the purpose of the research and what was expected of them prior to recruitment and their autonomy regarding participation was emphasised.

The focus groups were conducted in the first language of the majority of the participants. (English version of the consent form: Appendix C) Consent forms were available in Sesotho, isiXhosa, Afrikaans, and English.

4.3 Risks and Benefits

No significant risks have been identified in this study. Benefits included a broadening of knowledge as well as a better understanding of the topic. The participants were given the opportunity to ask questions about the topic to improve their own understanding. The participants did not receive any monetary gain from participating in the study.

4.4 Confidentiality

The group facilitator assured the participants that confidentiality would be maintained and that their identity will remain anonymous. The participants were allocated an assigned number for analysis to

accommodate this. The audio recordings, transcripts and any documents pertaining to the raw data is stored on a password protected flash drive. The flash drive will be stored for possible future reference.

Chapter 5: Results

In this chapter, the results obtained will be presented. The text in italics indicates direct quotes from the participants of the focus group discussions (FGDs). F1P1, for example, represents FGD one, participant one, as participants were assigned designated codes to maintain anonymity.

5.1 Study Population

A total of 55 foster parents were invited to participate. Initially,34 agreed to participate but only 28 eventually took part in the FGDs. Some reasons why potential participants did not attend included lack of transport, other prior commitments or that they forgot about the FGD. Table 5.1 reflects the sex and home language of the participants. More women than men participated, and most were Sesotho first language speakers.

Table 1 Summary of Participant's Sex and Language

	Sex			First Language				
	Male	Female	**Total**	Sesotho	Xhosa	English	Afrikaans	**Total**
Number of Participants	4	24	**28**	22	4	1	1	**28**
Percentage (%)	14	86	**100**	79	14	3.5	3.5	**100**

5.2 Focus Group Discussion

Five FGDs were held. Table 2 shows a summary of the number of participants and the main language spoken in each group.

Table 2Participant number and language of FGDs.

Focus Group	Number of Participants	Language FGD was conducted in
One	7	Sesotho
Two	6	Sesotho
Three	5	isiXhosa
Four	6	Sesotho
Five	4	Sesotho

From table two above it can be seen that focus group five only had four participants', this is smaller than the recommended FGD size. With the focus group being so small everyone still had the opportunity to express their beliefs, even though the information shared may have been limited. The data gathered from all five FGD was similar regardless of the group size. Different examples were used in the different groups; however, all themes were seen in all the focus groups.

5.3 Data Obtained from Focus Group Discussion

As discussed in the methods section, the audio files were translated and transcribed verbatim, the transcripts were then coded followed by grouping together similar findings. These groupings were then categorised into themes which are presented below.

5.3.1 Understanding of the Concept of Heredity and Genetics

There was some understanding amongst participants of what "heredity" means, however, there was less of an understanding of genetics or how heredity works. Participants often used the terms interchangeably.

Interestingly most participants gave behaviour as an example of heredity and believed that behaviour is passed on through the generations. Heredity was also seen as *"taking after"* a parent or grandparent. Below are some examples of what participants said about heredity:

> *"They have taken after their mother/ father,"*- F5P2
>
> *"It is when children take after their parent's personalities,"*-F5P3
>
> *"Heredity is something that comes from the family…… my husband is very clever, and his father was very clever,"*-F4P1

When participants spoke about genetics, many started by saying that they believed that genetics does exist and then would follow with an example of what makes them believe this. The examples ranged from diabetes to hearing and eyesight problems and included physical traits such as height as well as as behavioural traits.

"I believe that only some sicknesses can be passed on genetically. My mother had diabetes and I have diabetes. My family says I took (that) from my mother,"-F1P2

"I am a witness of this heredity topic; my entire family has sugar diabetes,"- F2P6

"When a child is born with hearing problems, it is said that it is in their genes, they have taken after their father/mother…" F5P2

There were, however, some participants that did not believe in genetics and others who expressed uncertainty.

"I have heard that some sicknesses can be passed on genetically, but I do not believe it is true," -F1P1

"This heredity topic is not yet clear to me. There is a lot I agree with and still a lot I do not agree with"-F4P4

Genetic conditions are seen by some participants as being "*in one's blood*" and therefore that nothing can be done to change the outcome.

" But I believe that if these sicknesses are in your blood, there is nothing you can do to stop them. You cannot change your blood. You cannot swop your blood with anyone." -F3P5

The participants were open to discussing their thoughts and beliefs and also had questions about the topic. One of the participants stated that when genetically related health problems arise in a family, the elders need to be consulted as the elders have all the knowledge.

Table four shows six phrases that were used often among all five focus groups. These phrases provide insight into the themes to follow.

Table 3Key Phrases that emerged in the FGDs.

Key Phrase	Sesotho Phrase
Bloodline	Madi a madi
In your blood	Ka hare hamadi a hao
Curse	Rohaka
Break the circle	Robasedikadikwe
Passed on through the generations	E fetilekameloko
Like father like son	Jwalokantateekameloko

5.3.2 Beliefs on Heredity

Five broad themes on the beliefs of participants emerged as illustrated in table four below. Each theme will be discussed in the context of the FGDs. Although the responses were grouped into themes, there is some overlap and some responses include aspects of more than one theme.

Table 4Major Themes

Theme	Examples
1. Lifestyle	Eating habits and exercising
2. Behaviour	Being ill-behaved
3. Familial	Clan inheritance, bloodline
4. Curses	Curses
5. Prevention and Management	Inheritance can be “broken”

5.3.2.1 Lifestyle

Lifestyle as a contributor to hereditary was the strongest theme that emerged from the data. Many participants believe that the apparent higher prevalence of genetic disorders seen today are due to lifestyle change. Participants pointed out that previous generations lived off the land and had meat and fruits and vegetables freshly available. Some participants even raised the point that the produce eaten by previous generations had not been treated with hormones and/or preservatives. They believe it is this change in lifestyle that can account for many of the disorders seen today. Lack of exercise was also seen as a cause of some diseases such as diabetes and high blood pressure. Interestingly blood pressure was often used as an example of heredity because a family history of hypertension is specifically asked for at primary health care clinics.

> *"It is the way we eat that causes us a lot of problems with many illnesses."*- F2P3
>
> *"…… it is the food we consume these days that makes us sick."* -F1P7
>
> *"At the clinic, they always ask about family history of blood pressure, is that not genetic*?"- F2P4

Other lifestyle factors that are believed to be the cause of genetic disorders are smoking and drinking while pregnant and not eating "correctly" while pregnant. Stress was also seen as a factor contributing to lifestyle disorders. Some participants also believed that these *"lifestyle sicknesses"* are passed on to the next generation, however, if the "cycle is broken", they will not be inherited by the next generation. This view of being able to stop passing on disease between generations sometimes had cultural or religious associations and will be discussed in more detail in the sections to follow.

> *"If you have a certain illness that is caused by your unhealthy lifestyle. It is passed on to your next generation due to them being from your bloodline,*" -F1P3

5.3.2.2 Behaviour

Behaviour was a common theme that all the groups mentioned. Behaviour was seen as the way in which people act, such as being mischievous or being caring. Many participants firmly believe that

behaviour is inherited. One of the participants even said that she can understand the behaviour of her biological children, but she has difficulty understanding her foster child's behaviour as he inherited it from his father. It is not only bad behaviour that is seen as being passed on but other attributes such as caring, wisdom, and intelligence are too. Participants said that the elders must be consulted when you do not understand your behaviour as perhaps there was a family member that behaved in the same way as you do and that the ancestors would know about that.

> *"If you find a child to be clever or to be a thief these days, it is likely that someone from previous generations was just the same."*-F3P3

> "*Sometimes you find that a child lives by fighting and never mingles with others. The child is always in retaliation and unnecessarily wearing an angry face. It is highly likely that someone from the previous generation had the exact same behavioural patterns."* -F3P4

5.3.2.3 Familial

Another belief the participants shared was that several characteristics are passed on in families. Physical characteristics were given as an example of hereditary traits that are passed on from generation to generation. They said that you can tell that a person belongs to a specific family because of their height or by having a distinctive nose; you can tell family association by resemblance. The concept of "*clan*[1] *inheritance"* suggests that family is seen as more than just immediate family. Behaviour was given as an example of clan inheritance.

> *"You will hear others saying that Bataung*[2]*like to always be fighting. Clan related hereditary moves from one generation to the next generations. You will find a number of members of a clan behave in a certain way as a result of another generation which had the same behaviour*

[1]Clan is a group of people who are related either by descent or kinship
[2]Bataung is one of the Sotho clans.

pattern some time back. When it is like that, it is not a family hereditary, but a clan hereditary." F4P4

"This is how the Mofokengs do things. This is how other clans do things. We hear people saying Barolong[3] like to sleep and these kids like to sleep." -F4P3

"Bloodline" was associated with heredity, but some believed that if a disorder is treated it will not be passed onto the next generation. Participants used "bloodline" to indicate that it is in their family and that by taking "bloodline" into account, disorders can be traced.

"To me, genes are something that is in your blood. For example, if you have a certain illness that is caused by your unhealthy lifestyle. It is passed on to your next generation due to them being from your bloodline"- F1P2

Another belief as to why there are genetic disorders is that the "*bloodline"* is incorrect and that the family is being punished.

There is also a belief that was expressed that poverty is inherited so no matter how hard a person tries to break out of the poverty cycle they will return to it as it is in their family. Poverty is also seen by some as a bad trait to inherit from parents.

"Just like poverty, poverty can be hereditary. You can find someone works for years and years earning loads of money, but they still remain poor only due to the fact that their parents or grandparents were very poor" -F3P3

5.3.2.4 Curses

The participants believed that some genetic disorders are caused by curses, especially if there was no family history of the disorder.

[3]Barolong clan in Tswana culture

"These (congenital disorders) do pass through to our children as they are curses, but by faith, we can break these curses."-F3P3

In one FGD there was a difference of opinion when it came to curses. One participant had this to say in response to genetic disorders being caused by a curse.

"Hereditary is natural. It is here to stay. That is no way to fight it. If it is bound to happen, it will happen. It is very important to accept it."-F1P5

There is a belief that some of these "curses" can be broken through prayer and rituals, but others cannot be broken.

"*It (heredity) is something that you can just stop…. I have found a way of stopping it."*-F1P6

"We have beliefs. If we believe that these kinds of things will not pass on to the next generation, they will stop." -F3P3

"… there is some genetics that can never be broken as they are in one's blood. There are also those that are cursed and those can be broken."-F3P4

There was also an idea expressed that if the first child is born with a genetic disorder, the second child will not have a genetic disorder. If the second child did have the disorder the belief was that it had nothing to do with genes but rather is the result of a curse. This was raised when a concerned mother asked if it was possible to have another child with a disability during the discussion about curses being the cause of genetic disorders. The group assured her that if her second child was born with a genetic disorder, it would be due to a curse and suggested this curse could be "broken".

Question: *"Because I already have a physically challenged child, is it possible that I may get another challenged child due to genetics?"*- F1P2

Answer: *"No, not necessarily. It will have nothing to do with genetics," (Group response to F1P2 question)*

Name giving was also seen as a reason for negative behaviour in that a child will fulfill the destiny of the name that they are given. Sometimes, if a child misbehaves, it is not because of heredity but because of the child's name and the "curse" that is tied to it.

> *"… it is not hereditary but a curse. You are cursing the child by giving them a bad name."*- F3P2

5.3.2.5 Prevention and Management

Participants believed that genetic disorders can be prevented. This was a prominent theme that occurred throughout the discussions and provides a link between the themes. There is a strong belief that the transmission of genetic disorders can be "broken" and therefore prevented from being passed on to future generations. This is believed to be possible through culturally based rituals, through prayers to God and through correct lifestyle choices including antenatal care.

> *"Heredity is in many families, but we can still break it……. when it comes to good characteristics, we cannot and should not break it,"*- F3P3

> *"We take if it is in the bloodline. We think that there was no one who broke the circle of those diseases; because if we take care of it, then it should stay like that,"*-F1P6

The participants who are religious believed that praying and asking God to protect a child will ensure that the child will not inherit any disorders.

> "*All we have to do is pray and ask God for it all to stop and not pass on to our kids."*–F3P5

Participants believe that God has the power to stop inheritance, and "break" the transmission.

> *"But as the bible says we can break the circle."* F3P3

> *"All you can do is believe that you will heal and stay positive all the time."*- F2P4

Some participants mentioned the importance of genetic screening prenatal care.

"It is very important that people constantly do tests to ensure that they do not transmit any ailments they may have to their unborn child." -F4P6

5.4Conclusion

In conclusion, participants were familiar with the term heredity, however, they use the terms genes and heredity interchangeably. The beliefs amongst the participants were similar. Participants frequently attributed causation of genetic disorders to lifestyle, cultural and religious reasons. There was also a belief that genetic disorders can be prevented, and inheritance of disorders and traits can be influenced through cultural and religious practice. Behaviour is strongly believed to be a trait that is inherited from previous generations. The results will be discussed in more detail in chapter six.

Chapter 6: Discussion

This chapter will discuss the results obtained. It will provide an overview of the study population and will give more insight into the results obtained.

From table, one it can be seen that first language Sesotho speaking participants made up most of the study population, with 79 percent of participants being Sesotho. isiXhosa speaking individuals made up 14 percent of the study population with English and Afrikaans a mere 3.5 percent each of the study population. This sample is not representative of the South African population, however, it is fairly representative of the study population of Welkom although Afrikaans speakers were underrepresented. According to the 2011 census, Sesotho is the most commonly spoken first language (58.3%) followed by Afrikaans (14.6%) and then isiXhosa (13.6%) in this area(2011 Census, 2011). The majority of the foster parents in the study were female (86%) which reflects the fact that in the foster parent database that was accessed to recruit participants most of the foster parents listed are female. Although the educational and economic background of the participants was not explored in this study, it could have influenced their beliefs.

The results demonstrated that participants had some understanding of the concept of heredity. It was understood to be “from one’s parents” or “from previous generations”. Genetics (genes) was seen as being “in one’s blood”. There was however limited understanding of what genes really are. Some participants said that genes “make you sick” and, although this is not completely wrong, their responses indicated that they do not understand the way in which gene function normally or cause diseases. In a study by Lanie et al. (2004), the authors noted that although the general public is exposed to many terms reflecting genetics, very few people have a good understanding of the concepts. The participants in their study conducted in the United States were either reluctant to answer or experienced frustration while trying to answer simple questions about the science of genetics leading to the conclusion by the authors concluded that participants had a limited understanding of basic genetic terms and concepts (Lanie, et al., 2004). The same conclusion can be

reached in this study. Participants acknowledged that they had heard the terms and did show a limited understanding of the term heredity but some participants specifically said that they do not know what it means or have an understanding of it and the discussions confirmed lack of detailed knowledge of genetics. When implementing a culturally sensitive healthcare system it is important to note that not all patients will understand typical used biological and scientific terms and that they may think that certain terms mean something different (Mikat-Stevens, Larson, & Tarini, 2015).

The concept of culture is complex and therefore the objective of investigating the role that culture plays in the understanding of heredity was not able to be determined depth in this study. It was clear though that some participants' beliefs did stem from cultural perspectives but the full understanding of the impact that culture has on a person's understanding of heredity was not determined in these FGDs. This may have been due to the small population samples well as not asking very specific questions related to culture during the FGD.

As seen in table three, the beliefs that participants expressed about heredity and genetics can be grouped into five main themes; lifestyle, behaviour, familial, curses and prevention and management. Each theme, as well as the links between the themes, will be discussed.

The participants compared how previous generations had lived and how people live today, a so-called "traditional lifestyle" versus a "modern lifestyle". The traditional lifestyle is seen as living off the land and eating fresh produce. The modern lifestyle is more about "quickly go to the shopping centre and buy the food required". Some participants believed that it are this change in lifestyle that causes some genetic disorders. They also believe that it is the "chemicals" that food is treated with that causes people to become sick. There was also a belief expressed that not eating the "correct" food while pregnant could cause a genetic disorder. Indulging in "forbidden" food has previously been identified as a potential cause of genetic disorders (Penn & Watermeyer, 2012).

Participants also had a belief that the "illnesses" caused by a person's choice of lifestyle may be passed on to the next generation. It was felt that such an illness would be in that person's blood from then

on and therefore in their bloodline. Participants did not completely disregard the biomedical model of causation of disease. They believed in biological causes of disease but integrate that with other models of disease causation including lifestyle choices. The limitations of a biomedical model in which a single cause for an illness may be assumed and where illness and disease are considered to be the same have been raised before suggesting a broader view of illness is more appropriate for most people's beliefs and experiences. (Wade & Halligan, 2004). The disorder that many of the participants used as an example of this thinking were diabetes. Many studies have confirmed that diabetes can run in families, not only because children can learn bad lifestyle habits from parents but there is also a result of a genetic predisposition to the disorder. Type two diabetes has a greater genetic component meaning there is a greater risk of first-degree relatives of an affected person developing type two diabetes than type one diabetes even though both have some hereditary component. (American Diabetes Association, 2017).

Choice of lifestyle was seen to play a role in inheritance mainly because the lifestyle that the ancestors use to live is no longer being followed. There have been many debates about eating like our forefathers, the so-called "true human diet". Debates continue as to whether it would actually be beneficial considering the lifestyle then and the fast-paced lifestyle we live in now(Ungar, 2017).

Most of the participants believed that certain genetic disorders are due to the family being cursed, especially if there is no family history of the disorder although there was not universal agreement on this and created dissent in one of the focus groups. The ancestors were believed to play a pivotal role in the prevention of genetic disorders. It is also believed by a number of participants that if the disorder was caused by a curse, it can be reversed or "broken", to ensure that it does not pass on to the next generation while others believed that a disorder may have been caused by a curse but that it cannot be broken. Only a few of the participants stated that they do not believe that genetic disorders are caused by curses.

It was not mentioned by this study's participants where these curses originate from, however, they indicated that to break a curse, certain prayers and/or rituals may be required. Some participants even said that through these prayers/rituals that they have personally managed to stop such a "curse" from spreading to their children. Such rituals will often be performed by a traditional healer who acts as a middleman between the patient and the spirits of the ancestors (Lange, 2018).

The belief in bewitchment or a curse being placed on the family as a cause of genetic disorders is well recognised in different populations. Witchcraft offers a context that allows people to make sense of events that cannot be explained. In South Africa, witchcraft is said to be the cause of disease and hard luck (Fottrell, Tollman, Byass, Golooba-Mute, & Kahn, 2012). In a qualitative study conducted in Ethiopia, that aimed at documenting the causes of mental disorders found that people believe curses and bewitchment to be one of the main causes for mental disorders (Teferra & Shibre, 2012).

Interestingly the participants believed that only certain "curses" can be broken. Although the discussion did not go into specific details, participants said that some genetic disorders can never be cured or broken as "it is in your blood" but some disorders that are caused by a curse can be broken and will therefore not pass on to future generations. Albinism is commonly believed to be caused by a curse and is an example where there is, for some, a belief that if a ritual is performed the "curse" will not be passed onto future generations(Phatoli, Bila, & Ross, 2015).

In South Africa, the beliefs around the cause of a disorder are often determined by cultural upbringing. The ancestors are often consulted in order to help to diagnose a disorder and also provide methods of treatment. Traditional healers will communicate with the ancestors to see if the disorder is perhaps due to the patient or family having broken cultural traditions. Rituals may then be performed to try to rectify the problem (Soloman, Greenberg, Futter, Vivian, & Penn, 2012).

The participants commonly described behaviourto be a heritable trait that could be passed on from previous generations. Some participants said that behavioural traits can stretch back hundreds of generations. The intergenerational transmission of behaviour was well illustrated by the participant

who pointed out that she can understand her biological children's behaviour but has difficulty understanding her foster-child's behaviour. She concluded that this is because the foster-child inherited the behaviour from his biological father. In the study by Soloman, Greenberg, Futter, Vivian, and Penn (2012) participants also believed that behavioural traits can be passed on from parent to a child.

Both negative behaviours and traits such as being intelligent, kind or brave were thought by participants to possibly be inherited. One participant gave an example of a child who was raised well but became a thief; she said that if one had to look back into the family history, you would probably find someone in previous generations who was a thief reflecting the strong contribution heredity is thought to play in behavioural traits. The belief is that a child should behave like their parents because they have inherited it from them. The saying "like father, like son" was used to describe this. The participants did not distinguish between "inherited" behaviour and "learnt" behaviour. In an article by Laden (2014), the author tried to explain why people may think that certain behaviours are inherited. He concluded that behavioural traits may seem to be genetic as when going back in generational time, behaviour does not seem to change. The author also made use of intelligence as an example of a heritable trait similarly to the participant in this study who believed her son was intelligent because his father was intelligent. The inheritance of behaviour is complex because of the added influence of environmental factors. Intelligence is one of the behavioural traits that are influenced by environmental factors and inheritance (Plomin & Deary, 2015). In many different countries, there is a widely held belief that intelligence is inherited. Cocodia (2014) reviewed the cultural perceptions of human intelligence and what intelligence means in Asian, African and Western cultures. Different societies view intelligence in different manners, therefore, the way an individual conceptualises intelligence will be determined by their culture (Cocodia, 2014).

Familial inheritance was also seen as sharing the same physical traits such as height. These physical traits indicate the resemblance between family members. Sharing traits are not just believed to be

within the family but was also thought to indicate “clan inheritance”. Clan inheritance is when members of a particular clan or common descent behave in a certain manner. A participant pointed out that you can see who belongs to a particular clan as they behave the same way.

Heredity is also believed to be part of the bloodline so if a certain trait is “in the bloodline” it will be passed on to future generations. Participants also believed that even if a disorder is in the bloodline, but itis treated then it will not be passed on to the next generation. This belief was more prevalent if the disorder was believed to be caused by a curse. In such cases, prayers or a ritual may be performed to ensure the disorder will not pass onto the next generation as the “bloodline” is now “cleansed” (Fouche, 2008).

There have been many studies done in South Africa to determine the ancestry of clans or tribes and such ancestry includes common cultural beliefs or practices. Indigenous knowledge such as stories that are passed down from generation to generation are important in such studies and may include stories of heritable behavioural traits. A well-known example of this is the Lemba clan who reside in Limpopo. Their oral history speaks of having Jewish ancestors, and the clan has similar practices to other Jewish population, such as eating kosher food. Genetic testing has also shown that there is Jewish origin within this clan (Soodyall, 2012) confirming there is often a genetic basis in the stories of heritable practices and behaviours.

Indigenous knowledge also affects what people believe, as some of the participants did say that if a behaviour can not be explained, the elders must be consulted. The elders of a clan are well respected and are the keepers of the indigenous knowledge. Indigenous knowledge plays an important role in primary health care as many people turn to traditional medicine as a source of healthcare (Issa, Owoeye, & Awoyemi, 2018).

Poverty was also believed by some participants to represent a form of familial inheritance and that some people still live in poverty as a result of previous generations being poor. They believe that no matter how hard that person tries to get out of poverty, they will return to it as it is in their family.

The idea that poverty is hereditary is not uncommon in South Africa, as it is often said that children of poor parents are more likely to become poor people themselves as poverty is transmitted from one generation to the next (Seabe, 2017). This again reflects the merging of genetic and environmental influences on commonly held beliefs.

The "curse" theme overlaps with the prevention and management theme in that most participants believed that genetic disorders can be prevented, however not by conventional methods. Many participants believed that genetic disorders can be prevented by performing rituals. Some participants even believed that a disorder could be "cured" through prayer and rituals. This finding is similar to the study of Soloman, Greenberg, Futter, Vivian, and Penn (2012) where participants claimed that rituals can be used to try to heal hemophilia.

Many participants also believed that God can protect children from getting genetic disorders and that one should pray to God and ask for protection for the child from developing genetic disorders. Prayer is also believed to be a way of preventing a disorder from being passed on from one generation to the next and some believed that praying can even heal someone. In a study conducted in Pakistan,95.8% of the 385 participants believed that prayers provide healing and 97.5% of the participants believed that prayers and medical treatment should be combined to provide holistic treatment (Qidwai, Tabassum, Hanif, & Khan, 2009).

In the study that was conducted by Penn et al. (2010) where traditional beliefs on the causes of various genetic disorders in South Africa were documented, the authors noted that many of the participants believed that God or ancestors were the cause of some genetic disorders. However, this study showed that neither God nor ancestors were "blamed" for genetic disorders, instead,they were seen as a way of providing prevention/ treatment of a disorder. This differs from what has been reported by Penn et al. (2010).

Only two participants commented on the importance of antenatal care and genetic screening as a means of prevention indicating the need for more education and health promotion in this area.

Chapter 7: Conclusion

In conclusion, cultural influences and beliefs play an important role in how people in the studied area understand genetics and heredity. There was some broad understanding of what heredity is amongst the participants, however, their beliefs influenced their understanding as heredity was not seen to be just biological.

The participants in this study considered lifestyle to be an important influence in heritability particularly in relation to multifactorial diseases like diabetes. Behaviourwas seen to be the most recognizable heritable trait to the participants and manifestation of multigenerational inheritance of behavioural traits was often used as a way of understanding a person's behaviour. The physical resemblance in families and recognition of the familiarity of disease as well as traits was also evident as an example of heredity to the participants.

Genetic disorders were often believed to be caused by curses in people from the ethnolinguistic groups represented in this study, however, a number of participants believed this can sometimes be "broken" or removed from a person or family using prayer and rituals. Ancestors play an important role in this. Many participants also held more traditional religious beliefs such as praying to God to protect a child from inheriting a disorder or negative trait or prevent transmission to future generations.

As seen from the literature review, it is important to have a health model that is patient-centered and that will encourage health-seeking behaviour. The participants in this study did not only accept the biomedical model of health as their social and cultural beliefs influenced their health behaviour. In order to provide genetic counselling to patients, genetic counsellors and health care providers have to be aware of their patient's beliefs and how it may influence their health behaviour. For example, if a patient believes that a disorder was caused by a curse, they may not follow through with a treatment plan as they will believe that only a ritual will cure them. Genetic disorders and congenital disorders

should be explained in a manner that the patient understands while respecting and considering their beliefs to improve the outcome.

Limitations of this study includes the small sample size. Additional data could have been obtained by allowing the participants to expand on the beliefs raised however, time was limited, and the facilitator focused on the questions of genetics and heritability to address the aim of the study.

For future studies, consideration should be given to include other ethnolinguistic groups and allowing more focus group discussion to expand on initial ideas. The focus group discussion could also include the elders of the community as it was said the elders “hold the knowledge” and including traditional healers of a community could add value. The themes of this study could provide a guide for a more detailed exploration that could help better understand the role that culture plays in the beliefs and understanding of heredity.

The limited knowledge and uncertainty that the participants expressed in the FGDs indicates strongly that there is a need for more public education on genetics and genomics and for genetic services that are sensitive to the beliefs of the population. Genetic counsellors should explore with their patients their beliefs and understanding of genetics during counselling in order to provide a comprehensive service that is also culturally sensitive to maximize the value to the patient.

References

Joubert, J., Rao, C., Bradshaw, D., Dorrington, R. E., Vos, T., & Lopez, A. D. (2012). Characteristics, availability, and uses of vital registration and other mortality data sources in post-democracy South Africa. *Global Health Action, 5*. doi:10.3402/gha.v5i0.19263.

2011 Census. (2011, October). Retrieved March 26, 2018, from Statistics South Africa: http://www.statssa.gov.za/?page_id=3839

ACOG Committee Opinion: 49. (2011, May). Cultural Sensitivity and Awareness in the Delivery of Health Care. *The American College of Obstetricians and Gynecologists, 117*, 1258-1261.

American Diabetes Association. (2017, January 27). *Genetics of Diabetes*. Retrieved June 2018, from American Diabetes Association: http://www.diabetes.org/diabetes-basics/genetics-of-diabetes.html

Ayode, D., McBride, C. M., de Heer, H., Wantabe, E., Gebreyesus, T., Tadele, G., . . . Davey, G. (2012). The Association of Beliefs About Heredity with Preventive and Interpersonal Behaviours in Communities Affected by Podoconiosis in Rural Ethiopia. *The American Journal of Tropical Medicine and Hygiene, 87*(4), 623-630.

Bagley, M. (2013, February 21). *Genetics: The Study of Heredity*. Retrieved January 2018, from Live Science: https://www.livescience.com/27332-genetics.html

Bamford, L. J., McKerrow, N. H., Barron, P., & Aung, Y. (2018). Child Mortality in South Africa: Fewer Deaths, But Better Data are Needed. *South African Medical Journal, 108*, 25-32.

Barber, N. (2015, September 24). *What Behaviours Do We Inherit via Genes?* Retrieved March 2018, from Psychology Today: https://www.psychologytoday.com/us/blog/the-human-beast/201509/what-behaviors-do-we-inherit-genes

Bhat, M. (2015). Social and Cultural Issues in Genetic Counselling. *Journal of Biosciences, 40*(2), 217-220.

Christianson, A., Howson, C. P., & Modell, B. (2006). *March of Dimes Global Report on Birth Defects.* New York: March of Dimes Birth Defects Foundation.

Cocodia, E. A. (2014). Cultural Perception of Human Intelligence. *Journal of Intelligence, 2*, 180-196.

Doody, O., & Noonan, M. (2013). Preparing and Conducting Interviews to Collect Data. *Nurse Researcher, 20*(5), 28-32.

Fisher, T. L., Burnet, D. L., Huang, E. G., Chin, M. H., & Cagney, K. A. (2008). Cultural Leverage: Interventions Using Culture to Narrow Racial Disparities in Health Care. *HHS Public Access, 64*(5).

Fottrell, E., Tollman, S., Byass, P., Golooba-Mute, F., & Kahn, K. (2012). The Epidemiology of "Bewitchment" as a Lay-Reported Cause of Death in Rural South Africa. *Journal of Epidemiology and Community Health, 66*(8), 704-709.

Fouche, M. (2008, September). *Spiritual Roots of Physical Illnesses and Diseases*. Retrieved July 2018, from Bloodlines: http://www.bloodlines.co.za/articles/spiritual-roots-of-physical-illnesses-and-diseases.html

Genetics Home Reference. (2018, March 6). Retrieved March 2018, from NIH U.S National Library of Medicine: https://ghr.nlm.nih.gov/primer/mutationsanddisorders/genemutation

Gillham, A., Greyling, B., Wessels, T.-M., Mbele, B., Schwyzer, R., Krause, A., & Mahlangu, J. (2015). Uptake of Genetic Counseling, Knowledge of Bleeding Risks and Psychosocial Impact in a South African Cohort of Female Relatives of People with Hemophilia. *Journal of Genetic Counselling, 24*, 978-986.

Greenberg, J., Kromberg, J., Loggenberg, K., & Wessels, T.-M. (2012). Genetic Counseling in South Africa. In D. Kumar, *Genomics and Health in the Developing World* (pp. 531-546). New York: Oxford University Press.

Hong, E. S., Zeeb, H., & Repacholi, M. (2006). Albinism in Africa as a Public Health Issue. *BMC Public Health, 6*(212). doi:10.1186/1471-2458-6-212

Hordern, J. (2016). Religion and Culture. *Medicine, 44*(10), 589-592.

Issa, A. O., Owoeye, P. O., & Awoyemi, O. O. (2018). Attitudes and the Practice of Documentation of Indigenous Knowledge By The Traditional Health Practitioners in Kwara State, Nigeria. *Library Philosophy and Practice (e-journal)., 1678*, 20 pages.

Kimbassa, N. (2013). Albinism in Africa. *Parliamentary Liason Office* (pp. 1-12). Cape Town: Southern Africa Catholic Bishop's Conference.

Kreuger, R., & Casey, M. A. (2015). Chapter 4: Participants in a Focus Group. In R. Krueger, & M. A. Casey, *Focus Groups: A Practical Guide for Applied Research* (p. 63*84). Singapore: SAGE.

Kriege, M., Brekelmans, C. T., Boetes, C., Besnard, P. E., Zonderland, H. M., Obdeij, I., . . . Klijn, J. G. (2004). Efficacy of MRI and Mammography for Breast-Cancer Screening in Women with a Familial or Genetic Predisposition. *The New England Journal of Medicine, 351*, 427-437.

Kromberg, J. G., & Jenkins, T. (2012). Ethical, Legal, and Sociocultural Issues and Genetic Services in Southern Africa. *Genomics and Health in the Developing World*, 585-590.

Kromberg, J. G., & Wessels, T. (2013). Roles of Genetic Counselors in South Africa. *Journal of Genetic Counselling, 22*, 753-761.

Kromberg, J. G., Sizer, E. B., & Christianson, A. L. (2013). Genetic Services and Testing in South Africa. *Journal of Community Genetics, 2013*, 413-423.

Kumar, S., & Preetha, G. S. (2012). Health Promotion: An Effective Tool for Global Health. *Indian Journal of Community Medicine, 37*(1), 5-12.

Laden, G. (2014, March 7). *Is Human Behavior Genetic Or Learned?* Retrieved June 2018, from Science Blogs: http://scienceblogs.com/gregladen/2014/03/07/is-human-behavior-genetic-or-learned/

Lange, G. (2018, February 7). *Different Types of Healers in South Africa*. Retrieved June 2018, from Culture Trip: https://theculturetrip.com/africa/south-africa/articles/different-types-healers-south-africa/

Lanie, A. D., Jayaratne, T. E., Sheldon, J. P., Kardia, S. L., Anderson, E. S., Feldbaum, M., & Petty, E. M. (2004). Exploring the Public Understanding of Basic Genetic Concepts. *Journal of Genetic Counselling, 13*(4), 305-320.

Lebese, V., Aldous, C., & Malherbe, H. L. (2016). South African Congenital Disorders Data, 2006 - 2014. *South African Medical Journal, 106*(10), 992-995.

Leung, F.-H., & Savithiri, R. (2009). Spotlight on Focus Groups. *Canadian Family Physician, 55*(2), 218-219.

Leventhal, H., Phillips, L. A., & Burns, E. (2016). The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-management. *Journal of Behavioural Medicine, 39*(6), 935-946.

Macleod, R. (2013, June 20). *It's in the Genes*. Retrieved December 2017, from eNews Channel Africa: https://www.enca.com/south-africa/what-sa-jolie-and-albino-share-need-genetic-counselling

Maguire, M., & Delahunt, B. (2017). Doing a Thematic Analysis: A Practical, Step-by-Step Guide for Learning and Teaching Scholars. *All Ireland Journal of Teaching and Learning in Higher Education, 8*(3), 335/1-335/14. Retrieved from the University of Auckland.

Malherbe, H. L., Aldous, C., Woods, D., & Christianson, A. (2016). The Contribution of Congenital Disorders to Child Mortality in South Africa. *South African Health Review*, 140-152.

Malherbe, H. L., Christianson, A. L., & Aldous, C. (2015). Need for Services for the Care and Prevention of Congenital Disorders in South Africa as the Country's Epidemiological Transition Evolves. *South African Medical Journal, 105*(3), 186-188.

Malherbe, H., Christianson, A. L., Aldous, C., & Christianson, M. (2016). Constitutional, Legal and Regulatory Imperatives for the Renewed Care and Prevention of Congenital Disorders in South Africa. *South African Journal of Bioethics and Law, 9*(11), 11-17.

Manga, P., Kerr, R., Ramsay, M., & Kromberg, J. G. (2013). Biology and Genetics of Oculocutaneous Albinism and Vitiligo – Common Pigmentation Disorders in Southern Africa. *South African Medical Journal, 103*(12), 984-988.

Mercè, I. (2017, January). *Advantages and Disadvantages of Focus Groups*. Retrieved May 2017, from Universal Teacher: http://universalteacher.com/1/advantages-and-disadvantages-of-focus-groups/

Mikat-Stevens, N. A., Larson, I. A., & Tarini, B. A. (2015). Primary-care providers' perceived barriers to the integration of genetics services: a systematic review of the literature. *Genetics in Medicine, 17*(3), 169-176.

Mitchell, K. (2018, January 5). *"Like father, like son": Testing folk beliefs about heredity in the arena of assisted reproduction.* Retrieved January 20, 2018, from Wiring the Brain: http://www.wiringthebrain.com/2018/01/like-father-like-son-testing-folk.html

Morris, M., Glass, M., Wessels, T. M., & Kromberg, J. G. (2015). Mothers' Experiences of Genetic Counselling in Johannesburg South Africa. *Journal of Genetic Counselling, 2015*, 158-168.

Musoke, D., Boynton, P., Butler, C., & Musoke, M. B. (2014). Health seeking behaviour and challenges in utilising health facilities in Wakiso district, Uganda. *African Health Sciences, 14*(4), 1046-1055.

Penn, C., & Watermeyer, J. (2012). Sociocultural Perspectives of Inherited Diseases in Southern Africa. *Genomics and Health in the Developing World Oxford Monographs of Medical Genetics*, 568-584.

Penn, C., Watermeyer, J., MacDonald, C., & Moabelo, C. (2010). Grandmothers as Gems of Genetic Wisdom: Exploring South African Traditional Beliefs About the Causes of Childhood Genetic Disorders. *Journal of Genetic Counselling, 19*, 9-21.

Phatoli, R., Bila, N., & Ross, E. (2015). Being Black in a White Skin: Beliefs and Stereotypes Around Albinism at a South African University. *African Journal of Disabilities, 4*(1), 1-10.

Plomin, R., & Deary, I. J. (2015). Genetics and Intelligence Differences: Five Special Findings. *Molecular Psychiatry, 20*(1), 98-108.

Puchalski, C. M. (2001). The Role of Spirituality in Health Care. *Proceedings (Baylor University Medical Center), 14*(4), 352-357.

Qidwai, W., Tabassum, R., Hanif, R., & Khan, F. H. (2009). Belief in Prayers and its Role in Healing Among Family Practice Patients Visiting a Teaching Hospital in Karachi, Pakistan. *Pakistan Journal of Medical Science, 25*(2), 182-189.

Rantanen, E., Pontinen, S., Nippert, I., Sequerios, J., & Kaarianien, H. (2009). Expertise, Empathy and Ethical Awareness: Ideals of Genetic Counseling Based on Framing of Genetic Information in International Guidelines. *New Genetics and Society, 28*(4), 301-316.

Sanderson, S. C., Waller, J., Humphries, S. E., & Wardle, J. (2011). Public Awareness of Genetic Influence on Chronic Disease Risk: Are Genetic and Lifestyle Causal Beliefs Compatible? *Public Health Genomics, 14*, 290-297.

Scotland, J. (2012). Exploring the Philosophical Underpinnings of Research: Relating Ontology and Epistemology to the Methodology and Methods of the Scientific, Interpretive, and Critical Research Paradigms. *English Language Teaching, 5*(9), 5-19.

Seabe, B. (2017, September 25). *A Poor Inheritance -- The Intergenerational Transmission Of Poverty*. Retrieved from The Huffington Post: https://www.huffingtonpost.co.za/busisiwe-seabe/a-poor-inheritance-the-intergenerational-transmission-of-poverty_a_23219285/

Shenton, A. K. (2004). Strategies for Ensuring Trustworthiness in Qualitative Research Projects. *Education for Information, 22*, 63-75.

Sinner, P., Prochazka, F., Paus-Hasebrink, I., Farrugia, A., & Farrugia, L. (2013, May 10). *What Are Some Good Approaches to Conducting Focus Groups with Children?* Retrieved March 2018, from University of London International Programmes: http://www.lse.ac.uk/media@lse/research/EUKidsOnline/BestPracticeGuide/FAQ/FAQ-34.pdf

Sobiecki, J. (2012). Psychoactive Ubulawu Spiritual Medicines and Healing Dynamics in the Initiation Process of Southern Bantu Diviners. *Journal of Psychoactive Drugs, 44*(3), 216-223. Retrieved from South African Ethnobotany.

Soloman, G., Greenberg, J., Futter, M., Vivian, L., & Penn, C. (2012). Understanding of Genetic Inheritance among Xhosa-speaking Caretakers of Children with Hemophilia. *Journal of Genetic Counselling*. doi:10.1007/s10897-012-9495-9

Soodyall, H. (2012, November). *We Were All Africans: Stories About Our Past Engraved on Our DNA*. Retrieved June 2018, from Human Sciences Research Council: http://www.hsrc.ac.za/en/review/hsrc-review-november-2012/We-were-all-Africans-Stories-about-our-past-engraved-on-our-DNA

Stewart, D. W., & Shamdasani, P. N. (2014). *Focus Groups: Theory and Practice* (Third ed.). Los Angeles: SAGE Publications.

Teferra, S., & Shibre, T. (2012). Perceived Causes of Severe Mental Disturbance and Preferred Interventions by the Borana Semi-nomadic Population in Southern Ethiopia: A Qualitative Study. *BMC Psychiatry, 12*(79). doi:10.1186/1471-244X-12-79.

Truter, I. (2007). African Traditional Healers: Cultural and Religious Beliefs Intertwined in a Holistic Way. *South African Pharmaceutical Journal, 74*(8), 56-60.

Ulin, P. R., Robinson, E. T., & Tolley, E. E. (2005). Chapter 2: The Language and Logic of Qualitative Research. In P. R. Ulin, E. T. Robinson, & E. E. Tolley, *Qualitative Methods in Public Health: A Field Guide for Applied Research* (1st ed., pp. 19-31). San Francisco: Jossey-Bass.

Ulin, P. R., Robison, E. T., & Tolley, E. E. (2005). Chapter 1: Invitation to Explore. In P. R. Ulin, E. T. Robinson, & E. E. Tolley, *Qualitative Methods in Public Health: A Field guide for Applied Research* (1st ed., pp. 4-6). San Francisco: Jossey-Bass.

Ulin, P. R., Robison, E. T., & Tolley, E. E. (2005). Chapter 4: Collecting Qualitative Data. In P. R. Ulin, E. T. Robinson, & E. E. Tolley, *Qualitative Methods in Public Health: A Field guide for Applied Research* (1st ed., pp. 98-113). San Francisco: Jossey-Bass.

Ungar, P. (2017, April 17). *The "True" Human Diet*. Retrieved September 2018, from Scientific American: https://blogs.scientificamerican.com/guest-blog/the-true-human-diet/

Visser, M., & Booysen, F. (2004, November). Determinants of the choice of healthcare facility utilised by individuals in HIV/AIDS-affected households in the Free State province of South Africa. *Centre for Social Research Working Paper 87*.

Wade, D. T., & Halligan, P. W. (2004). Do biomedical models of illness make for good healthcare systems? *British Medical Journal, 329*, 1398-1401. Retrieved from Wiley.

White, P. (2015). The Concept of Diseases and Health Care in African Traditional Religion in Ghana. *HTS Teologiese Studies / Theological Studies, 71*(3), 7 pages.

Witherington, S. (2014, August 20). *10 Reasons Why Genetic Screening is Important*. Retrieved March 2017, from I, Have Lych Syndrome: http://www.ihavelychsyndrome.org/10-reasons-genetic-testing-important/#.WMboZIVOLIU

World Health Organisation. (2014). *Traditional, Complementary and Integrative Medicine*. Retrieved June 2018, from World Health Organisation: http://www.who.int/traditional-complementary-integrative-medicine/about/en/

World Health Organisation. (2015, September 7). *Congenital Anomalies*. Retrieved April 2018, from World Health Organisation: http://www.who.int/news-room/fact-sheets/detail/congenital-anomalies

World Health Organisation. (2016, March). Retrieved March 2018, from Promoting health through the life-course: http://www.who.int/life-course/news/events/world-birth-defects-day/en/

Appendix A: HREC Approval Letter Reference 802/2017

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6626
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Website: www.health.uct.ac.za/fhs/research/humanethics/forms

19 January 2018

HREC REF: 802/2017

Dr K Fleggen
Human Genetics
Room 4.23
Falmouth Building

Dear Dr Fleggen

PROJECT TITLE: CULTURAL BELIEFS ON HEREDITY IN WELKOM, FREE STATE (MPhil-candidate- C Davies)

Thank you for submitting your response to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 January 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student, Clare Davis will also be involved in this study.

Yours sincerely

PROFESSOR N BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical

Appendix B: Focus Group Guideline

± 10 minutes per question

Introductory Questions:

1. What is your understanding of the term “heredity”?
2. What do you know about genetics?
3. Do you know of any congenital disorders? If so, which ones?

Main Focus:

1. Why do you think people look the way they do?
2. Why do you think family members sometimes look so alike?
3. How do you think physical characteristics are passed on from generation to generation?
4. What role do you think genetics plays in heredity?
5. Why do you think babies are born with those disorders (as mentioned earlier)?
6. Do you have any specific beliefs about genetics?

Probes:

1. What are your thoughts on what **A** said?
2. Can you give more detail?
3. **A** said this, **B** what is your opinion?

Appendix C: Consent Form

This form consists of of **TWO** parts.

A copy of the form will be provided to you.

PART 1: Information

This information sheet serves to provide you (the participant) with all the relevant information about the research project at hand. If there are any words that you are unsure of or would like the further explanation at any point during consent taking, please feel free to ask at any stage.

Introduction:

My name is Chantè Davies, I am a master's student at the University of Cape Town. For degree purposes, I need to conduct a research study. The research project I have chosen is to document the beliefs that people have regarding inheritance.

As we live in a very diverse country, beliefs about different aspects of health may differ vastly. For example, I may have certain beliefs about why I have high blood pressure, but my parents do not have blood pressure problems. My beliefs will differ from yours. This is what this study aims to do: to find out what the beliefs are surrounding genetic inheritance.

Below is a further explanation of the study:

What is the purpose of the study?

Everyone has different beliefs about genetic inheritance, and it is these beliefs that the study will document. The study aims to broaden the knowledge of what people believe regarding genetic inheritance.

How will the study be conducted?

If you consent to take part in the study, it will be a focus group. This will entail a group discussion between 5 -8 participants that will last for about **1-1½ hours** the discussion will be led by the community worker and I will be present for the discussion.

Are there risks involved in taking part in the study?

There are no major risks involved in taking part in the study.

What are the benefits of taking part in the study?

There is no material benefit (You will not be paid to take part in the study). However, it can be an enriching experience and an opportunity to learn more about the topic.

Who will be taking part in the study with me?

The other participants will also be foster mothers from your community.

Will my answers remain secret?

Yes, although the group discussions will be voice recorded, your name won't be attached in any way to any comments that you make. The recorded files will be stored safely.

More on your rights:

1. Participation is voluntarily
2. Should you no longer wish to participate at any point in time, you may withdraw from the study.
3. Your beliefs will be respected.
4. Focus groups will be conducted in your home language.

Should you require any more information kindly do not hesitate to contact me on 082 5868 681 or email davieschante@yahoo.com.

PART 2: Consent Form

Certificate of Consent:

Participant Consent:

I have been invited to take part in the study "Beliefs on heredity in Welkom, Free State":

I have read the foregoing information, I have had the opportunity to ask questions, and any questions asked, have been answered to my satisfaction. I understand what is expected of me.

I consent voluntarily to partake in this study and that it is my understanding that answers will remain anonymous.

Signature: _____

Date: _____

Statement for consent taker:

I have to the best of my ability ensured that the potential participate fully understands their rights to participate in the study and understands what the study entails. I confirm that the participant was given the opportunity to ask questions and that the questions were answered to the satisfaction of the participant. I confirm that the participant has not be coerced into giving consent, and that participation was given freely.

Name of Consent taker: _____

Signature: _____

Date: _____